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Psychological Sexual Health of People with Paraplegia

Stefano Federici, Francesco Artegiani, Daniele Diotallevi, Giovanna Caruso and Alessandra Castellani Mencarelli

Abstract

People with paraplegia have to fight their own and societal attitudes and stereotypes that reduce sexuality to the physiological functions of genitalia. These psychological and social limitations arise from cultural and disability models that focus sexual pleasure on phallocentric primacy, and sexual attractiveness of perfect bodies. In this chapter, we evaluate the impacts of a psychoeducational intervention in a personal growth group on the sexual life of two groups of people with spinal cord injury (SCI) and their partners, throughout their sexual interest and satisfaction, depression, and anxiety. In the first study, nonparametric statistical tests were used to compare pre- and post-outcome measures for all participants. In the second study, the grounded theory was used to explore dialogs and activities that were audiotaped during the group meetings. The participants in both groups were patients and their partners. The psychoeducational intervention was clearly effective in increasing sexual interest and satisfaction as well as the motivation and ability to enjoy sexuality. Anxiety was minimized for all participants, although it may not have been associated with the psychoeducational intervention. In addition, the intervention significantly improved the partner and patient group's opportunity and ability to enjoy sexuality.

Keywords: spinal cord injury, sexuality, sex stereotypes, biopsychosocial model, sexuality and disability, people with paraplegia

1. Introduction

When someone has experienced spinal cord injury (SCI), the first question they often ask is, "Doctor, will I ever walk again?" The thought soon after—sometimes never verbalized—emerges with equal urgency: "Will I be able to have sex?" This question is not answered easily, although the slogan of the American Consortium for Spinal Cord Medicine [1] exhorts to believe that "No injury, no matter how serious, can take away your ability to have a relationship, experience love, and experience the attraction between two people" (p. 3). People with SCI face many difficulties to regain confidence in themselves and their ability to experience intimacy and affection [2]. These challenges do not just emanate from the genital dysfunction caused by the injury, including alterations or loss of genital sensation, or erection, ejaculation, lubricate, and orgasm [3, 4]. They also arise because they must rediscover a new way of pleasure to themselves and others by learning to

inhabit a body that in many ways is new and dissimilar and requires a different way of touching, caressing, and exploring themselves and their partner [4].

In addition to this difficult adjustment to changes, like many other people with disabilities, people with SCI have to battle with their own and societal attitudes and stereotypes that deny individuals with disabilities are sexual beings [4, 5]. Such attitudes and stereotypes are the results of two pervasive and interrelated misconceptions (myths), which very often influence human thinking and behavior: bodily perfection [6] and asexuality [7–10]. These two myths arise from a disability model that is often known as the medical model of disability [11, 12], whereby people are deemed disabled due to their medical condition or impairment [13, 14]. Therefore, disability is understood as an individual inability to conform to a standard of normality, namely when the abnormality occurs within the person [15], making him/her different from the majority of people [16].

According to this (medical) disability model, people with SCI have a disability in sexual relations due to the limitation or lack (resulting from the injury) of ability to conduct sexual activity in the manner that is considered normal or ideal [17]. Here, the interrelation between bodily perfection and sexual activity is closely and precisely related. ‘Able’ people have to see the person with SCI as asexual because the injury obviously has affected the capacity to perform the so-called normal sexual activity. Conceiving sexual activity by a person with a disability for a ‘normal’ population would mean admitting to imagine an abnormal (monstrous) sexuality [8, 18].

The myths of bodily perfection and asexuality of disabled persons are not mere social constructions that influence attitudes and stereotypes. Every cultural context and historical period encompasses an ideal of bodily beauty and sexual behavioral norms [19]. Therefore, we should find such myths as universal human convictions [20, 21] that emerged from psychological mechanisms that evolved to solve long-enduring adaptive problems characteristic of the ancestral human environment [22]. Mating with someone who is unhealthy could pose a range of adaptive risks to our ancestors, including transmitting communicable diseases or viruses, impacting survival and reproduction, infecting children, and jeopardizing the children’s chances of survival and reproduction [23, 24]. Hence, human survival was guaranteed by an evolved psychological mechanism to avoid contact and sexual intercourse with persons with visible deformity [25, 26]. Park et al. [27] found that individual differences in disease perception predict immediate cognitive responses that connect physical disability to disease (medical model) and also predict behavioral avoidance (disgust) of people with physical disabilities. Meloni et al. [28] also found a relationship between an evolved disease avoidance mechanism and contemporary prejudices that affect individuals with physical disabilities.

It should be noted that the field of psychiatry has a specific term for the sexual attraction to the body of a person with a disability: *devotism*. This concept is considered suspect and, to a certain extent, pathological; it is classified as a paraphilia in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition [29].

Another signal that the medical disability model might act as an innate psychological mechanism below the two cultural constructs of bodily perfection and asexuality, as a cognitive constraint [30], is the occurrence of disability explanation compatible with the medical model early in childhood [31–33], independent of parents’ disability representations and explanations [13].

Like the nondisabled, most people with SCI have grown up believing that disability is deviance and that bodily perfection is the standard [34]. As Susan Wendell wrote in her famous autobiography book *The Rejected Body* [19], to identify oneself

as a disabled person requires a change in one's own personality and a radically new way of thinking about oneself. The SCI is almost always a devastating event with many life-changing consequences, all of which require a number of changes during their post-injury lives [35, 36]. Sexual adjustment to SCI is one of those problems that is closely related to body image [2], general psychological health, overall self-esteem [37, 38], and body attractiveness [10, 39].

In a male-centered patriarchal culture [40]—characterized by unequal relationships between men and women (polarization) and power distribution (androcentrism), and biological essentialism (i.e., gender and roles vary by nature) [41]—the sex most people get to know is totally phallocentric (penis centered). According to Freud [42], around the age of five, children become aware that they either possess a penis or do not possess a penis and that having a penis is “a proud possession” [43]. Conversely, for women, the absence of a penis makes them “victim to envy for the penis” [42]. The recognition that one has or does not have a particular set of genitals is, for Freud, tantamount to recognizing the gender to whom they belong. “I have a penis” means “I am a boy” and “I do not have a penis” means “I am a girl.” In this system, the gender identity is a genital (penis-centered) identity. As Rubin [44] wrote,

“The alternative presented to the child [to have a penis or to be castrated] may be rephrased as an alternative between having, or not having, the phallus. [...] The presence or absence of the phallus carries the differences between two sexual statuses, ‘man’ and ‘woman.’” (p. 191)

This penis orientation relates to the awareness that having and using erections has something to do with masculinity [45]. Therefore, “males are in constant danger of losing their manhood and their identities” [45] when the erectile functions are compromised. As testified by Tepper [9], a sexuality educator and counselor living with SCI, “[T]he man with erectile dysfunction, inhibited ejaculation, loss of sensation, or physical limitations might conclude that his sex life is over.” (p. 45).

Extensive research on erectile functions and male sexuality has largely overlooked the female sexuality of women with SCI [39, 46, 47]. This phenomenon is not surprising within Judeo-Christian androcentrism that restricts the sexual role of a woman to a reproductive function within the family and the ability to stimulate and satisfy a man's own sexual appetite [41]. This view denies women the experience of sexual pleasure [48]. Given that SCI neither compromises the receptive function of female sexual organs nor a woman's reproductive capacity [1], the biggest issues for women after SCI is usually focused on the perceived attractiveness of their bodies [39], that is, as a function of male sexuality. In an androcentric, penis-centered sense of sexuality—that Tom Shakespeare [49] defined as the “fucking ideology”: heterosexual and penetrative intercourse with a male on top of a female—characterizing Judeo-Christian androcentrism, loss of genital sensation does not compromise a woman's sexual role. The Austrian philosopher Otto Weininger, a Jew who converted to Christianity in 1902 and who became a real posthumous celebrity within the German-speaking cultural world of the early twentieth century and beyond, in his popular and influential book on sex and character [50] published in 1903, explained the difference between a mother and a prostitute, woman's polar attributes (*sic*), “The mother does not experience sexual intercourse any *less* than the prostitute, but *differently*. The mother's behaviour is mainly receptive and accepting, while the prostitute feels and savors the pleasure to the extreme” (p. 205; emphasis in the original). Far from it, the loss of genital sensation ensures the woman's virginal and chaste role [48] (see also the traditional

practice of female genital mutilation in Islamic cultures that involves more than 200 million girls and women in 30 countries worldwide: https://www.unicef.org/media/files/FGMC_2016_brochure_final_UNICEF_SPREAD.pdf). Alexander and Rosen [51] and Komisaruk and Whipple [52] provided other evidence of a different focus on the sexuality of women with SCI compared to men. Women are oriented to giving rather than receiving pleasure. As both studies found, the major sexual concern of women is the diminishing opportunity and ability to give their partner sexual fulfillment because the disability disfigured the beauty of their body. Moreover, according to Kettl et al. [39],

“The biggest and most remarkable change [for women] after spinal cord injury in our study was the worsening in body image. This was far greater than any change in ratings of sexual practice or enjoyment.” (p. 294)

Given that the sexual role of a woman in patriarchal cultures is restricted to the attractiveness of their body as a function of male sexuality, in a reverse sense, this factor can also be their shame. In fact, a woman's attractiveness is perceived similarly to penis erection, that is, a sexual behavior: when a male finds an attractive body, then sex is allowed because the former is a function of the latter. As LaRocca and Kromrey [53] found, male students consider an event to be more harassing when the victim was unattractive (read, not sexually available) compared to when the victim was attractive (read, sexually available). This stereotype is certainly no less affecting in women's judgment, who consider an event as more harassing when the victim was attractive (if sexually available, why violence?) than when the victim was unattractive (because of sexual unavailability, male violence allowed). Thus, Golden reports [54] that an action by an attractive male directed toward an unattractive female is more likely to be identified as not harassing. From a recent survey conducted by the Italian National Institute of Statistics [55] on stereotypes on gender roles and the social image of sexual violence, the prejudice that blames the woman for their suffered sexual violence still persists. For instance, 23% (without gender differences) believe that women can cause sexual violence with their way of dressing (read, their attractiveness). Therefore, it is not surprising that the main sexual concern of women with SCI is to have a body that is no longer attractive, no longer capable, that is, of giving their partner the 'right' sexual pleasure, and run the risk of deserving violence. Still in a recent survey conducted in the United Kingdom, Thrussell et al. [56], in accordance with previous literature, reaffirm that for women with SCI.

“satisfaction with body image was reduced. To look ‘sexy’ was difficult [...]. Lacking confidence and feeling sexually unattractive during rehabilitation was common; support and opportunities to improve self-confidence, self-esteem, body image and social skills were identified as essential.” (pp. 1088–1091)

The aim of this chapter is to provide data for the Love & Life project that was collected from two interventional studies led by two growth groups. The project was performed in the Unipolar Spinal Unit of the 'S. Maria della Misericordia' hospital in Perugia (USU-PG). This unit is one of the 22 spinal units that comprise the Italian National Health System, of which 9 are unipolar. Love & Life aims to enhance the psychological sexual health of USU-PG in- and outpatients and their partners. To achieve this goal, the project follows the biopsychosocial sexual health model of the World Health Organization [57, 58] and human functioning [59]. This positive, holistic, and comprehensive view states that sexual health is “a state

of physical, emotional, mental, and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction, or infirmity” ([58], p. 3). This view implies overcoming the reduction of the medical model and its socio-cultural products (myths, attitudes, stereotypes, and prejudices), which restrict sexuality to the physiological function of genitalia, phallogentric primacy of sexual pleasure, and attractiveness of only bodily perfection. The Love & Life initiative facilitates a psychological (emotional and behavioral) change, which increases self- and sexual esteem and satisfaction. By promoting a psychoeducational personal growth group [60], people with SCI and their partners can experience, express, and rework thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, roles, and relationships about sexuality [58].

This project was approved by the ethics committee of the Department of Philosophy, Social & Human Sciences, and Education, University of Perugia. The project information was disseminated both orally and in paper format. Written informed consent was recorded for each group member on a prepared form by participant signature.

2. Study 1

2.1 Setting

The inpatients were recruited from the USU-PG by the psychologist working in the unit between November and December 2017. All inpatients admitted to the USU-PG received a brochure with the goal of the Love & Life initiative, participation requirements, topics for the sessions on sexual life in the personal growth group, schedule of meetings, and leaders’ names and phone numbers. The same content was also presented in a poster format in unit corridors and in other hospital departments. In the same time, IR also recruited outpatients from the USU-PG patient registry by phone. The personal growth group on sexual life met in the USU-PG wheelchair accessible rehabilitation room from December 2017 through May 2018.

2.2 Participants

The inclusion criteria for attending the Love & Life personal growth group on sexual life were the following:

- Age \geq 18 years
- Provide voluntary written informed consent
- USU-PG in- and outpatients with a traumatic SCI (para- or tetraplegic), with or without a partner
- Current partner (wife, husband, or sexual partner) of in- and outpatients of USU-PG who attended the Love & Life personal growth group

We use ‘participants’ to refer to all those who attended the growth group on sexual life and ‘patients’ to refer to both inpatients and outpatients. Fourteen participants attended the growth group on sexual life from December 2017 to May 2018. Only 11 participants were included in the present study, as explained in Section 2.7 (the subsection ‘Sample’).

2.3 Measurements and procedures

A sociodemographic questionnaire and three outcome measures were self-administered (see below) by participants and their partners who had provided voluntary written informed consent during the recruitment process. The outcome measures were administered again at the end of the last group meeting.

Sociodemographic questionnaire. This form was developed *ad hoc* to collect data on participants' age, gender, sexual orientation, type of SCI (para- or tetraplegia), civil status, children, education, employment, citizenship, political orientation, and religious beliefs. The sexual orientation was rated on the Kinsey scale [61], also called the Heterosexual-Homosexual Rating Scale. It ranges from 0 to 6, with '0' indicating exclusively heterosexual/opposite sex behavior or attraction and '6' indicating exclusively homosexual/same-sex behavior or attraction. Ratings 1–5 are for those who report varying levels of attraction or sexual activity with either sex. The sociodemographic questionnaire was administered to all participants once, before the start of the first group meeting.

Sexual Interest and Satisfaction (SIS) scale. This measure is a six-item scale designed to measure sexual adjustment after SCI [62]. It is used to assess interest in and satisfaction with sexuality before and after injury [63]. Partners of the participants with SCI were instructed to answer the questions by making reference to before and after their partners' injury. Participants are asked to give answers on a scale of 0 (non-existent/very dissatisfying) to 3 (increased/very satisfying). This sexuality scale is one of the few that has been used within the SCI population [64]. Only one study [62] reported validity and reliability properties of the scale on a sample of 73 SCI subjects (60 male; mixed injury types; SCI duration >1 year). The SIS scale showed a high correlation with age at injury and moderate-to-high correlation with quality of life, and a high internal consistency (Cronbach's $\alpha = 0.96$).

Beck Depression Inventory-II (BDI-II). In its current version, the BDI-II is a 21-question multiple-choice self-report inventory that comprises items relating to symptoms of depression such as hopelessness and irritability, cognitions such as guilt or feelings of being punished, and physical symptoms such as fatigue, weight loss, and lack of interest in sex [65]. Scores for statements ranged from 0 (e.g., "I do not feel sad") to 3 (e.g., "I am so sad or unhappy that I can't stand it"). Higher total scores indicate more severe depressive symptoms. The reliability and validity of the BDI-II in the Italian population have been demonstrated [65].

Beck Anxiety Inventory (BAI). This measure was designed to differentiate anxiety from depression [66]. The respondents indicate how much they have been bothered by each of the 21 symptoms during the past week. Symptoms include the inability to relax and trembling hands. Respondents rated each symptom on a scale ranging from 'not at all' (0) to 'severely' (3). The reliability and validity of the Italian BAI have been demonstrated [67].

2.4 Structure, content, and techniques of the psychoeducational intervention

The personal growth group met every fortnight for a total of 12 meetings, each of which lasted for 2 h. The sessions were held by psychologists and psychotherapists with expertise in sexuality and disability. The group meetings were organized in two parts: informative and practical. The informative part covered six topics, each for two meetings: (i) Me and my new body, (ii) Affective-relational communication, (iii) Between identity and sexual orientation, (iv) Discovering pleasure, (v) Live sexual life, and (vi) Aids to pleasure. The contents were also transmitted through the projection of videos and sexually explicit images, starting from the assumption that observational learning has an informative and motivational

function [68–71]. The interactive practical part—dedicated to personal growth and body awareness—utilized cognitive-behavioral therapy, Gestalt therapy, and emotion-focused therapy techniques. Through the cognitive-behavioral therapy techniques (e.g., problem management, role-playing, imagery, and modeling) [72], Participants were driven by the cycle of creating thoughts and emotions associated with their own sexuality to address stereotypes and derogatory beliefs about sexuality and disability, masturbation, orgasm, pleasure, sexual fantasy, sexual identity, and the beauty and attractiveness of the body. This process included the identification of possible dysfunctional patterns of self that negatively influenced the relationship with their partners. This effort meant overcoming the reductionist view that stems from both the disability medical model, which limits sexuality to the physiological functions of genitalia and genital sensation as the only possibility for sexual experience and heterosexism. Through Gestalt therapy [73] and emotion-focused therapy techniques [74], the emergence of a new sexual concept has been reinforced by increasing awareness on bodily feelings, stressing the relationship and the cycle of reflection on exciting emotions to create new meaning. For example, we used an empty chair and the imagination of the participants to develop and direct dialogs to help them reconcile contrasting aspects of their experience, pay attention to the body and verbal language, concentrate on emotions and the here and now of the relationship with the therapist or other group members. See the Supplementary Material to [63], where two topic guides are provided as an example of two group meetings on sexual life.

2.5 Apparatus

During the personal growth group meetings, a computer (Lenovo, ThinkPad T560), projector (Epson EB-S05), and wireless speaker (JBL Clip 2) were used to watch educational videos and images and perform some psychology exercises (e.g., visualization and relaxation exercises).

2.6 Data analysis

All data were processed using IBM SPSS Statistics for Windows, Version 25 (Armonk, NY). Due to the small sample size, nonparametric statistical tests were used. Specifically, the Wilcoxon test for paired samples was used to compare pre- and post-intervention scores on the SIS, BDI-II, and BAI for the complete sample (participants) and the two sub-groups (patients and partners).

To determine the effect size of the intervention, r was used, which was calculated by dividing the z value by the square root of N (number of cases used in the analysis). The interpretation of r values for effect size is relatively similar to Cohen's d [75]. It was considered negligible if it was less than 0.10, small from 0.10 to 0.30, medium between 0.30 and 0.50, and high if it was greater than 0.50. Although we used nonparametric statistics for the analyses, means and standard deviations of the variables (instead of the median) were reported whenever possible. An independent sample Kolmogorov-Smirnov test was also used to compare the patients and partners groups and consider possible gender effects.

2.7 Results

Sample. Three out of fourteen male participants who signed the informed consent and participated in the group meetings did not complete the complete sociodemographic questionnaire and/or outcome measures. Therefore, they have been excluded from data analysis. Of the remaining 11 participants (female: $N = 6$,

54.5%; male: $N = 5$, 45.5%), 4 males had complete paraplegia, 1 female had complete tetraplegia, and 1 female and male each had incomplete paraplegia. All of them were outpatients during the group activity. For all participants, the cause of SCI was traumatic (years from injury: $M = 38.1$; $\min = 26$; $\max = 50$; $SD = 9.44$). All four partners of the participants with SCI were females. The 11 group participants included 4 couples (8 individuals). One female participant with SCI reported not having a romantic or sexual partner.

Outcome measures. All participants ($N = 11$) improved significantly on SIS scale item 5 (“How are your opportunity and your ability to enjoy sexuality yourself?”; $z = -3$; $p < 0.01$), SIS scale total score ($z = -2.53$; $p < 0.05$), and BAI scores ($z = -1.99$; $p < 0.05$). The effect size was high in all cases ($r = 0.90$, $r = 0.76$, and $r = 0.60$, respectively). There was no difference in the scores for the SIS general satisfaction after injury or BDI.

A significant effect was found on SIS scale item 5 (“How are your opportunity and your ability to enjoy sexuality yourself?”) for both patients ($N = 7$; $z = -2.24$; $p < 0.05$) and partners ($N = 4$; $z = -2$; $p < 0.05$) with a high effect size ($r = 0.84$ and $r = 1$, respectively). There were no effects for the total score or general satisfaction after injury for the SIS scale, BDI-II, or BAI. Further, there were no significant differences between genders or patients and partners. See [63] for more details on the pilot data of Study 1.

3. Study 2

3.1 Setting and participants

Recruitment procedures and eligibility criteria for participation were the same as in Study 1. The personal growth group on sexual life met from January to June 2019 in the rehabilitation room of the USU-PG; it is accessible to wheelchairs. Only 7 participants were included in the present study, as explained in the subsection “Sample.”

3.2 Measurements, procedures, and apparatus

The self-administered sociodemographic questionnaire, outcome measures, procedures for administration, and structure, content, and techniques of the psychoeducational intervention were the same as in Study 1. A Sony ICD-PX312 audio recorder was added to the apparatuses described for Study 1 (Section 2.5) to record the dialogs of each meeting. The CONSolidated criteria for REporting Qualitative studies (COREQ) checklist was followed in reporting the results [76]. The COREQ checklist is available at [77].

3.3 Data analysis

Outcome measures. Nonparametric statistical tests were used due to the small sample size (Wilcoxon test for paired samples), and the r to determine the effect size of the intervention interpreted similarly to Cohen’s d [75], as in Study 1.

Qualitative data. In grounded theory, data collection and analysis occur simultaneously [78]. The 12 meetings of the personal growth group were all audiotaped by two independent researchers (GC and ACM). All audio recordings from the 24 meetings were then transcribed, carefully read, and indexed according to the grounded theory coding procedure [78, 79]. To investigate the effects that the psychoeducational intervention has had on the participants’ sexual health, the most significant verbal expressions were identified, and a code/index was assigned to each

one through a three-phase-inductive logic procedure, by studying the topic within its context and using an emerging design. See the Supplementary Material, where the codebook and detailed qualitative data analysis of each meeting are reported [77].

The reliability of codes was evaluated through measuring intercoder agreement, assessing the degree of trustworthiness of each code assigned to the same portion of text by GC and ACM. The level of agreement between two researchers was assessed using Krippendorff’s alpha for nominal items [80]; reliability was considered optimal if $\alpha \geq 0.800$, suboptimal with $\alpha \geq 0.667$, and non-optimal otherwise (Table 1).

The manual text analysis was transferred to Atlas.ti software (version 8.4) to measure intercoder agreement and calculate the occurrences of the categories and their relevance. Finally, through the software, the codes that emerged from the transcriptions of each meeting were compared to evaluate any differences in the theoretical construct that characterized them. By detecting how the codes developed with the progression of the meetings, it was possible to infer the effect of the psychoeducational intervention on the participants’ sexual health.

3.4 Results

Sample. One male and one female (out of nine participants) who signed the informed consent and participated in the group meetings did not complete the entire sociodemographic questionnaire and/or the outcome measures. Therefore, they were excluded from data analyses. Of the remaining 7 participants (female: $N = 1$), 2 males had complete paraplegia, 2 males had complete tetraplegia, 1 male had incomplete paraplegia, and 1 male had incomplete tetraplegia. Five of them were outpatients during the group activity. For 5, the cause of SCI was traumatic (years from injury: $M = 8$; $\min = 0.75$; $\max = 11$; $SD = 3.03$). The participating female was the partner of a male with SCI, the only couple in the group. Three male participants with SCI reported not having a romantic or sexual partner.

Outcome measures. Although not significant, there was an increase in the raw values for all participants ($N = 7$) on SIS scale item 5 (“How are your opportunity and your ability to enjoy sexuality yourself?”; $M = 1.29$ – 3.57), SIS scale total score ($M = 10.86$ – 13.14), and SIS scale general satisfaction after injury score ($M = -1.57$ to -2). The effect size was medium in all cases ($r = 0.36$, $r = 0.46$, and $r = 0.60$, respectively). There were no significant differences in the scores for BDI-II and BAI and between genders or patients and partners.

Semantic domain	Krippendorff’s Cu- α /cu- α	Krippendorff’s c- α -binary
Efficacy of therapeutic intervention	0.822**	0.885**
Rehabilitation of sexuality	0.945**	0.793*
Difficulties from exercises	0.900**	0.818**
Disability experience	0.951**	0.832**
Sexuality experience	0.887**	0.796*
Relationship	1.0**	0.774*
Perceived support	1.0**	0.853**
Total	0.788*	0.951**

*Suboptimal agreement.
**Optimal agreement.

Table 1.
Level of agreement between the two independent evaluators, as scored using Krippendorff’s alpha.

Qualitative analysis assisted by Atlas.ti. The findings resulted in the core category ‘psychological sexual health after SCI’ and identified the experience of evolving sexuality during the personal growth group. Three main themes were identified, supported by seven categories: (1) disabled sexuality, (2) influences of family and social environment, and (3) effects of psychoeducational intervention. As shown in the diagram below (**Figure 1**), the three themes can be assumed to represent three stages of the same process—each one inextricably influenced by the others—and resulting in the ultimate purpose of the intervention, namely to achieve sexual health after SCI.

Theme 1—Disabled sexuality: “I don’t know how your body can react to my caress, it’s not like before.”

Participants expressed their experience of sexuality as influenced by their impaired body. They reported psychological experiences related to living with a disability or with a partner with a disability, a phenomenon that negatively influenced daily life and sexuality, compromised the possibility of giving and receiving sexual pleasure, and hampered the ability to experience intimacy and affection after SCI.

Disability was experienced as an element that leads to an imbalance in the life of the person with SCI and their family, causing anger, anxiety, depression, difficulties in self-regulation of emotional states, and caregivers’ psychophysical exhaustion.

It was better that I hadn’t been saved from the accident [...] I would have felt nothing, and 11 years would have passed, that the people who love me wouldn’t. (DM).

There was a constant focus on past life, which was valued more positively than present life, often due to encountering difficulties in accepting disability (one’s own or her or his partner’s), discomfort, and negative self-perception. In fact, physical changes in sexual function and masturbation emerged.

Initially, I had written only a couple of problems related to masturbation, which were those of lack of sensitivity, [...] of not achieving orgasm as before and therefore this created small desire and small excitement, so small desire to masturbate. (DP).

I wouldn’t feel pleasure if I touched myself or someone touched it [my penis]. (DM).

It often happens to me that it [my penis] thinks the way it thinks, and I think different from it [...] I can’t see if I can put this [my penis] and this [my head] in synergy. (SF).

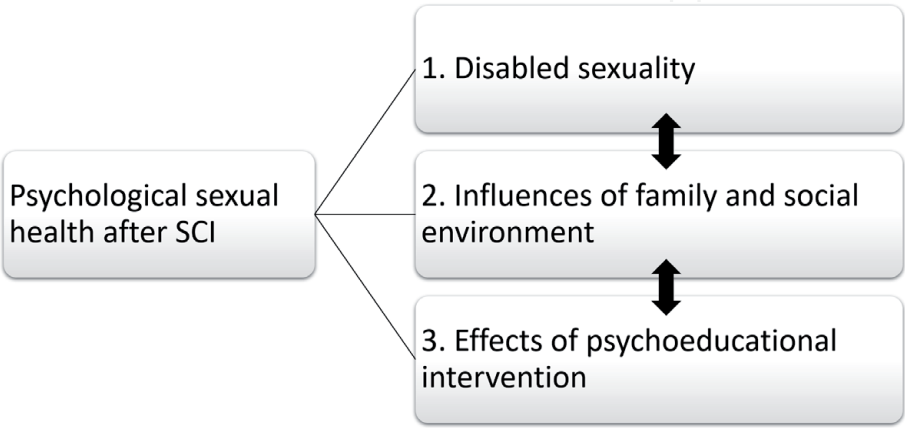


Figure 1.
Core categories resulted by the qualitative analysis assisted by Atlas.ti and their inter-relationship.

Related to masturbation before the accident and afterwards, it became almost completely absent for me, right? Because it doesn't give me, to this day, the same satisfaction that it did before. (DP).

Unfortunately, I haven't tried them [sensations] now, because I don't have the use of my hands and nothing, I can't even think about masturbating right now. (SA).

The participants presented common stereotypes about sexuality and consequent experiences with the topic: performance anxiety, sexual dissatisfaction, loss of interest, and perception of not being attractive.

I was the first one to call myself asexual or disabled (DP).

I can't... I couldn't, I mean, or I could more hardly woo a girl and then tell her to go get a pizza, and then I probably couldn't do what I was able to do when I was 30. (SP).

Finally, there were two opposing attitudes: sexual desire and fear.

I caress him (my partner with SCI) in the face and I feel something moving inside of me, but it doesn't go... it can't go any further. It can't... and then I think back to the past. And from there I get stuck. (GA).

Theme 2—Influences of family and social environment: “I’ve seen them look at me differently.”

Familial, social, and professional relationships influenced sexual dialog with current or future partners. The participants expressed that there were changes in relational experiences and reflections on the perceived level of support.

The participants reported role changes within the family and conflicts in relationships.

At home I did everything, I was the fulcrum. (SA).

Now we talk to each other all the time with something... a little bit of anger, of... if he doesn't want to talk, shut up like he used to, and I'll raise my voice. (GA).

Furthermore, the participants expressed difficulties in finding a romantic/sexual partner, and disability was described as a cause of being discriminated.

I believe, from a purely subjective point of view, that not all, I speak of the female counterpart, have a detail, that is 'patience'. About knowing problems of who is in a wheelchair and then get to normal sexual intercourse, or... develop fantasies about being in a wheelchair and whatever else. (FC).

There was someone I haven't seen in a long time. When he saw me, I felt like I had the worst disease in the world from the look on his face. (SF).

Many people always see only the wheelchair; they don't see the person, the wheelchair as an inanimate object. I just need it to carry that person... not that person, that pile of muscle, bones and whatever else from point A to point B. (FC).

The participants also reported that they did not receive enough support (familial and institutional) in coping with the changes brought about by their disability. Others felt supported by family members and found the psychological support received in the rehabilitation process and in the personal growth group important.

I am working a lot, swimming pool, gym, all private clearly, because it is useless, after 3 years I have seen them all. (SA).

Even my children, they can't understand my anger. (GA).

[My partner] is sincerely facing this sexuality on her part, this sexuality [...] in general, she is facing this problem with extreme naturalness, tranquillity, and positivity. (SF).

Thanks to you, professionals, who have been supportive along the way. (FC)

Theme 3—Effects of psychoeducational intervention. “I have discovered that sexuality is not only physical, but there is also the more satisfying aspect, which is, really, that which goes beyond the physical part.”

This theme includes the effects that the intervention had during personal growth. Starting from the expectations of the participants, there were moments in which the therapeutic environment proved to be effective in achieving its goals. At other moments, the group showed difficulties during the exercises.

The therapeutic environment was effective in changing the participants' state of activation. It provided relaxation and well-being and presented strategies and new perspectives that increased self-esteem.

I feel that there are a lot of things to do, and it has given me a line, a direction. I was really looking for it. (SA).

I did a good job. I also felt some emotions, perhaps crossing the eyes of SA., or FA... [...] and it made me feel good emotions. (SF).

Maybe more self-esteem? That is, if I was on a certain level of self-esteem and courage [...], the encounters have given back a bit of lymph in being able to deal face-to-face this kind of topic with a person. (FC).

The exercises stimulated insight and introspection. Sharing within the group was considered by the participants as a means of enrichment.

I realize [...] how limiting was my past way of doing. I understand very well the potential of the mind and how restricted was the vision of sexuality that I had before with respect to what could be or is. [DP].

The most encountered difficulties concerned the expression of personal experiences or those related to the intimate sphere, exercises of imagination, and auto analysis, the latter for members in whom the exercises evoked thoughts related to the traumatic event and past life.

When we started talking about sexology, my head went haywire. (GA).

By doing this, in quotes, experiment happiness took my breath away. (DM).

Finally, the intervention stimulated motivation to recover sexual health after SCI, with an emphasis on the relational component rather than the physical component of the sexual experience. The participants demonstrated that they understood the importance of exploring the body and resources, as well as the possibility of developing compensatory mechanisms and sexual assistance.

With my partner every little sign that approaches sexuality is amplified, every caress, every word, every gesture enters me with amplified power. (SF).

My new sexuality can be a caress, a kiss, a “thank you”, a word in need... this is sexuality for me now. The closeness, the awareness of being together and interacting, sometimes. Together. (GA).

To be aware that, sexuality is not something that just sits there. We talked about physicality, but it finds its own progression also through other... other forms of... sharing, of participation. (SP).

Let [the sexual assistant] help me or reveal some secrets, some little tricks so that I can interact with him. (GA).

4. Discussion

The two studies provided pilot data on the effectiveness of a psychoeducational intervention for the sexual life of two groups of in- and outpatients and their partners performed at the USU-PG. We would like to emphasize that the first noteworthy outcome of this project (Love & Life) was the realization of an initiative aimed at promoting the sexual life of people with SCI in an Italian public health facility. As far as we know, this project was the first in Italy to tackle the issue of improving sex life and not just treating sexual dysfunction of people with SCI. Given the novelty of the initiative, we have had to battle with deep psychological, cultural, and religious reluctance to accepting the treatment of sexuality as an inherent aspect of personal well-being that no trauma can eradicate. Breaking the resistance of people (disabled and non-disabled, patients and partners, health workers and laypeople) even to consider that people with SCI also have the capacity to have relationships, experience love, and experience sexual and romantic attraction was a big deal. Having said that, 23 people's involvement is already reflective of the effectiveness of our initiative.

4.1 Sex, education, religion, and other characteristics of the participants

Although the composition of the personal growth groups on sexual life was not defined in any way by the criterion of representativeness of the Italian population to the SCI, some of the characteristics of the sample tend to be compatible with the main SCI data. For instance, the prevalence of males with SCI in the group reflected the worldwide male-to-female ratio (4:1) [81, 82]. Only one participant (Study 2) has reached a master's degree level, only one a bachelor's degree (Study 1), and six a high school diploma (Studies 1 and 2). This finding is consistent with another key fact: SCI is associated with lower rates of school enrolment [83].

Except for one patient (Study 2), the cause of SCI was traumatic. The mean age when the traumatic event occurred was 37.2 years, data that are consistent with Pagliacci et al. [81] on the Italian SCI population (38.5 years). Ten participants declared that they were Roman Catholic, five from Study 1 and five from Study 2. Two of them (Study 1) were a lesbian couple with a civil union. The remaining participants declared themselves non-religious. In the two samples studied, the Catholic affiliation was lower than the national average—74.4% according to Ipsos Public Affairs [84]. Dealing with a sexually explicit topic seems to attract more people who do not have a religious affiliation or an orthodox view (e.g., lesbian couples in civil unions) because religions have specific sex teachings that can condemn masturbation or sexual relations outside of a heterosexual marriage [1, 19, 45, 49, 85–87].

4.2 Outcome measures and effect size

The effectiveness of the psychoeducational intervention was clearly apparent, denoted by a high (Study 1) or medium (Study 2) effect size in improving sexual interest and satisfaction as well as the opportunity and ability to enjoy sexuality. Anxiety was also reduced for all participants in Study 1 but not Study 2, although this outcome may not have been related to the psychoeducational intervention. Conversely, the intervention did not appear to significantly reduce levels of depression in patients or partners (Studies 1 and 2). This result might be clarified by the fact that the level of anxiety reported at the beginning of the first group meeting may be influenced by the context of novelty and sensitivity of the topic. When the re-test was carried out at the conclusion of the last group meeting, the climate was more friendly and the issue of sexuality less concerning. Hence, the decreased levels of anxiety could be more due to an intervening variable (anxiogenic context) than to treatment effectiveness. This potential fact could also explain why there has been no improvement in the levels of depression, which usually tends to positively correlate with anxiety [66, 88]. Indeed, the personal growth group on sexual life was primarily focused on improving awareness of sexuality conveyed by sexually explicit videos and therapy techniques focused on feelings and social relationships. Anxiety and depression might be determined by many other factors [88] that affect the quality of life of the patients and, consequently, their partners, besides sexual function, interest, and satisfaction. In addition, an efficacious psychotherapeutic treatment for observing reduced anxiety and depression might require more than 12 meetings over a period of 3 months [89, 90]. However, our findings correspond to the study by Harrison et al. [91] in which anxiety and depression were experienced by the same individuals, and anxiety—but not depression—was related to the sexual dysfunction of a woman with SCI.

4.3 Qualitative data (study 2)

The effectiveness of the psychoeducational intervention also clearly emerged from the qualitative analysis because it has promoted a path of self-confidence (“The encounters have given back a bit of lymph in being able to deal face-to-face this kind of topic”) and it shattered prejudices about sexuality (“I understand very well the potential of the mind and how restricted was the vision of sexuality that I had before”).

The three themes that emerged from the qualitative analysis are consistent with those elements highlighted in the Introduction. Sexuality emerged as closely linked to one’s own and other’s perception of the functioning and image of the body. A disabled body has disabled sexuality [92]. Recovering sexual health involves regaining the image of one’s body and confidence that one can still give and receive pleasure [2, 4].

It is also clear from the qualitative analysis that stereotypes do not only concern nondisabled people toward people with disability; they also affect the people with disability themselves (“I was the first one to call myself asexual or disabled”) [4, 5]. Finally, the adjustments that every person with SCI must tackle to regain their sexual health inevitably pass from the quality of social relationships (“Many people always see only the wheelchair”), ranging from the recovery of intimacy with the partner to trust in their own attractiveness.

5. Conclusions

Several studies [5, 9, 93–96] and guides [1, 4, 68] urge that adequate education [96] and psychological support [97] be provided to people with SCI in order to

facilitate successful participation in sexual activities. These studies also highlight the need to involve intimate partners in discussions related to sexuality during the rehabilitative process [96] in an inclusive approach that gives women—in the same way as for males—the opportunity to talk with peers with SCI about sexual health during the initial rehabilitation and after returning home [98]. The first and greatest achievement of the Love & Life project was to develop, in Italy, an environment where a psychoeducational intervention could meet the needs of people with SCI, provide adequate education and psychological support, include partners, and create a space for peer-to-peer interaction. The intervention effectiveness also offers strong, clear evidence of the validity of the accepted biopsychosocial model that overcomes a reductionist view that restricts sexuality to the function/dysfunction of genitalia, phallogentric primacy of sexual pleasure, and attractiveness of only perfect body. We do not believe we have solved the complexity of the sexual lives of women [99] and men with SCI and their partners, but we hope that the Love & Life initiative will lead to a new way forward to address this complexity.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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